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ORIGINAL ARTICLE

An Exploratory Study to Describe Transgender People with HIV Who Accessed Medicaid and Their Viral Suppression Over Time in New York City, 2013–2017

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Abstract

Purpose: Although HIV surveillance contains information on HIV outcomes among transgender persons with HIV (TPWH), it does not include other important data, for example, gender-affirming health care, which may influence viral suppression (VS). We describe TPWH accessing Medicaid and the association of gender-affirming surgery with VS.

Methods: Through matching Medicaid claims with HIV registry data, a cohort of previously identified TPWH in Medicaid was compared to cisgender women and men in terms of VS in 2013–2017 in New York City. Medicaid claims were used to identify TPWH who obtained gender-affirming surgery (e.g., chest, genital surgeries). We described the VS of those who had surgery and examined temporal trends in VS pre- and postsurgery and by surgery type.

Results: 1730 TPWH were enrolled in Medicaid and in HIV care in 2013–2017. Overall for VS at last laboratory, TPWH in Medicaid had lower VS (76.0%) than cisgender women (80.4%) and men (83.3%). The exception was the 185 TPWH who obtained gender-affirming surgery (86.5%). Among 160 TPWH in Medicaid who obtained gender-affirming surgery and achieved VS, VS increased presurgery (66.3% 2 years prior, 76.9% 1 year prior) and remained high 1 year after (86.3%) and 2 years after (87.7%) (the last percentage is only among those who had surgery before 2017, $N = 81$).

Conclusion: Gender-affirming surgery may be an important motivator to becoming virally suppressed and was associated with sustained high VS, which can lead to improved survival and quality of life. Medicaid and other insurers should consider improving access to gender-affirming surgery among TPWH.

Keywords: gender-affirming surgery; HIV; Medicaid; surveillance; transgender people; viral suppression

Introduction

Important inequities exist for transgender persons with HIV (TPWH) in New York City (NYC). In 2019, 3% of newly diagnosed PWH were transgender and TPWH had the lowest proportion of sustained HIV viral suppression (VS); 50% for TPWH compared to 70% for cisgender men and 67% for cisgender women.[1] Recognition of health-related inequities led to the NYC Health Department adding transgender gender identity in its HIV registry in 2005. The 2015 NY Ending the HIV Epidemic (EtE) Blueprint[2] called for an integrated and comprehensive approach to TPWH health. This requires measurement of a wide range of variables, and yet, this remains challenging when data sources are siloed, exclude transgender gender identity, and/or report on a limited set of variables.

To address these challenges, a match between Medicaid and the NYC HIV registry was conducted, augmenting the strengths of each.[3] With over 260,000 cumulative cases, the NYC registry is the largest and

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oldest population-based local HIV registry. It is based on legally mandated reporting and involves multiple quality assurance processes, thus reducing issues of selection bias and missingness. Medicaid provides health coverage to low-income populations.[4] Medicaid does not include transgender gender identity, but it reflects greater comprehensiveness in terms of health issues than the HIV registry and it is a critical safety net program; 67% of PWH are enrolled in Medicaid in NYC.[5]

To identify transgender persons in Medicaid, verified methods for identifying transgender persons in administrative datasets were utilized,[6–8] using diagnosis codes, prescription drugs, sex, and restriction and exception codes. This was followed by a match to the HIV Registry, which was the first to identify TPWH in NYC Medicaid. We found that 6335 transgender persons accessed Medicaid in 2013–2017; 1764 (28%) of whom were diagnosed with HIV.[3] Most TPWH in the HIV registry had accessed Medicaid (79%) and 79% of TPWH accessing Medicaid were correctly identified as transgender in the registry.

The match laid the groundwork to explore the characteristics of TPWH accessing Medicaid, which is a timely issue, particularly since a ban on Medicaid coverage of gender-affirming surgery was reversed in NY in 2015.[9] We first focus on gender-affirming surgery as it has been reported as a top health concern among TPWH nationally[10] and access to it has the potential to improve overall wellbeing and HIV outcomes. Gender-affirming surgery may be associated with improved mental health,[11] which is critical to engagement in HIV care.[12] Research suggests that VS may improve among TPWH when their gender is affirmed and they have had empowering health care experiences.[13] Also, yet, we are not aware of any published studies assessing the association between gender-affirming surgery and VS.

Therefore, this exploratory analysis aimed to describe (1) the demographic characteristics and prevalence of VS among those in HIV medical care among TPWH accessing Medicaid compared to cisgender women and men; and (2) the prevalence of VS before and after gender-affirming surgery among TPWH enrolled in Medicaid who had accessed gender-affirming surgery, in NYC.

Methods

Data and analysis

Only PWH who received HIV medical care, were alive by January 1, 2013, and were diagnosed by December 31, 2017 were included. TPWH accessing Medicaid from the prior analysis were our focus.[3] Although we were unable to assess if cisgender persons in the HIV registry had accessed Medicaid, as a full match between Medicaid and the HIV registry was not possible, we included cisgender PWH for reference to compare their VS to that of TPWH in Medicaid. Demographic data from the registry included gender, race/ethnicity, age, area-based poverty, area of birth, and borough of residence in 2017.

Area-based poverty is defined as the percent of the population in a ZIP code whose household income is below the Federal Poverty Level per the American Community Survey 2013–2017.[14] If individuals died before 2017, age and borough of residence at death were used. As a routine analysis of HIV registry data, this analysis was deemed exempt by the NYC Department of Health and Mental Hygiene Institutional Review Board. All descriptive analyses were conducted using SAS 9.4.[15]

Demographic characteristics and VS

We describe VS and demographic differences among the following: TPWH who accessed Medicaid, a subpopulation of TPWH who obtained gender-affirming surgery through Medicaid, cisgender women with HIV, and cisgender men with HIV. Cisgender PWH are a combination of persons who did and did not access Medicaid. VS was defined as an HIV viral load with a value of <200 copies/mL. "Overall VS" was based on the last laboratory test for each individual between 2013 and 2017. Our denominators for VS were those "in care" (a CD4 or viral load laboratory result between 2013 and 2017). We also included VS from the last viral load test for each year to describe the VS trends over time.

Identifying TPWH in Medicaid who accessed gender-affirming surgery

Procedure codes from Medicaid claims in 2013–2017 were used to identify those who accessed gender-affirming surgical procedures. Codes included the Current Procedural Terminology codes in the Gender Reassignment Surgery Model National Coverage Determination and inpatient surgical procedure codes from Canner et al. that we mapped from International Classification of Diseases (ICD)-9 codes to ICD-10 codes.[16]

We examined VS by type of surgery: chest, genital, and facial feminization. Chest surgery was defined as procedures performed on the chest (e.g., mammaplasty,

the augmentation of breasts using prosthetic implant, code 19325). Genital surgery were procedures performed on the genitals (e.g., orchiectomy, the removal of the testes, code 54520). Facial feminization procedures were cosmetic modifications of the face or throat (e.g., reshaping of bone, cartilage, or tip of nose, code 30410). TPWH may have had more than one type of procedure.

Pre- and postsurgery VS

Due to the anecdotally reported common practice of requiring VS before surgery, we wanted to delve deeper into the subset of TPWH that achieved VS at last laboratory and had obtained surgery in the 2013–2017 period. We were interested in describing their VS pre and postsurgery, since it may drop over time if the motivation for VS was based solely on obtaining surgery. It could also show, for example, whether they maintained high VS over time regardless of timing of surgery.

We assessed VS 1 and 2 years before providing presurgery VS history, taking the last viral load result at least 2 years before the first procedure date and the last viral load between 1 and 2 years before the first procedure date. For 1-year postsurgery, we took the first viral load between 1 and 2 years after the last procedure date. We had to further subset our analysis to assess VS 2 years postsurgery because viral load results were not available past March 2019 at the time of this analysis. VS 2 years postsurgery was available only for TPWH who had a gender-affirming surgical procedure in 2013–2016.

Among those TPWH, we assessed VS based on the first viral load at least 2 years after the last procedure date, up through March 2019. The use of first and last procedure time points accounts for the fact that TPWH may obtain multiple procedures over time and this method was utilized in a large study of mental health care utilization postaffirming surgery among transgender persons in Sweden.[11]

Results

Demographics

Approximately half of the 1730 TPWH in Medicaid were black, 64.8% were living in higher-poverty areas, and the highest percentage (39.5%) lived in the Bronx, the borough with the highest levels of poverty and rates of new HIV diagnoses in NYC (Table 1). A greater proportion of those who obtained gender-affirming surgery identified as black (57.3% vs. 50.8%); a smaller percentage identified as Latino/Hispanic (34.6% vs. 40.1%); and most were aged 30–39 (39.5% vs. 32.4%), lived in very high-poverty areas (44.3% vs. 39.1%), and in Brooklyn (34.6% vs. 25.6%).

Medical care and VS

Of the 98,334 PWH who received HIV care in 2013–2017, TPWH enrolled in Medicaid accounted for 1.7% (1730) of all PWH; of the 1730 TPWH, 185 (10.7%) accessed gender-affirming surgery. In 2017, VS was 75.4% among all TPWH enrolled in Medicaid (an increase of 13.0% from 2013), 85.1% among the subset who accessed gender-affirming surgery (an increase of 11.7% from 2013), 82.2% among cisgender women (an increase of 8.7% from 2013), and 85.5% among cisgender men (an increase of 6.9% from 2013) (Table 2).

VS pre- and postsurgery

Among the 160 (86.5% of the 185 TPWH who accessed surgery) TPWH who received surgery and were virally suppressed at their last laboratory in 2013–2017, VS was 66.3% 2 years prior and 76.9% 1 year before first procedure date (Fig. 1). VS was 86.3% 1 year postsurgery and 87.7% 2 years postsurgery (for the latter percent this is among those who had procedures before 2017, $N=81$), for an increase of 32.2% over the total pre- and post-time period. Eleven of the 160 TPWH did not have viral loads reported postsurgery and none died in the postsurgery period. VS varied by surgery type, with those who received both chest and genital surgeries having the highest VS pre- and postsurgery. There were only 10 TPWH who accessed facial surgeries; therefore we did not assess VS for this group.

Discussion

The VS of TPWH who accessed Medicaid rose more rapidly than among cisgender PWH over the 5-year period, but it was consistently lower. At 75.4% in 2017, it was 10.1% points lower than cisgender men (85.5%) and 6.8% points lower than cisgender women (82.2%), in addition to being slightly lower than for all TPWH regardless of Medicaid use (76.5%).

A higher proportion of TPWH in Medicaid than cisgender populations were made up of subpopulations that face intersecting inequities that generally have lower VS, such as those whose race is black and live in high-poverty areas. The disparity in VS suggests that prioritizing the health of transgender persons should remain a priority as NY state and local health

Table 1. Demographics of People with HIV Who Are in HIV Care in 2013–2017 in New York City, Comparing Transgender Persons Who Accessed Medicaid to Cisgender Women and Cisgender Men

	Transgender persons in Medicaid							
	All ($N=1730$)		Those who had gender-affirming surgery ($N=185$)		Cisgender women[a] ($N=26,706$)		Cisgender men[a] ($N=69,640$)	
People with HIV characteristics	*N*	%	*N*	%	*N*	%	*N*	%
Demographics of those in care[b]								
Gender according to HIV registry								
Men	266	15.4	11	5·9	0	0.0	69,640	100.0
Women	30	1.7	1	0.5	26,706	100.0	0	0.0
Transgender persons	1434	82.9	173	93.5	0	0.0	0	0.0
Trans woman	1413	98.5	167	96.5	0	0.0	0	0.0
Trans man	21	1.5	6	3.5	0	0.0	0	0.0
Race/ethnicity								
Black	878	50.8	106	57.3	15,688	58.7	27,401	39.3
Latino/Hispanic	694	40.1	64	34.6	8871	33.2	23,061	33.1
White	108	6.2	7	3.8	1651	6.2	16,721	24.0
Asian/Pacific Islander	31	1.8	5	2.7	360	1.3	1907	2.7
Native American	5	0.3	[c]	[c]	63	0.2	198	0.3
Multiracial	14	0.8	[c]	[c]	53	0.2	256	0.4
Unknown	0	0.0	0	0.0	20	0.1	96	0.1
Age group								
0–12	6	0.3	0	0.0	36	0.1	42	0.1
13–19	6	0.3	0	0.0	157	0.6	206	0.3
20–29	417	24.1	41	22.2	1546	5.8	6261	9.0
30–39	561	32.4	73	39.5	3095	11.6	12,232	17.6
40–49	364	21.0	46	24.9	5707	21.4	13,968	20.1
50–59	301	17.4	20	10.8	9549	35.8	21,518	30.9
60+	81	4.7	5	2.7	6616	24.8	15,413	22.1
Area-based poverty								
Low poverty (<10% below FPL)	64	3.7	7	3.8	1600	6.0	6140	8.8
Medium poverty (10% to <20% below FPL)	462	26.7	43	23.2	6988	26.2	23,000	33.0
High poverty (20% to <30% below FPL)	445	25.7	51	27.6	6444	24.1	15,522	22.3
Very high poverty (≥30% below FPL)	676	39.1	82	44.3	8651	32.4	15,505	22.3
Area-based poverty level not available	83	4.8	2	1.1	3023	11.3	9473	13.6
Area of birth								
United States	1270	73.4	135	73.0	15,461	57.9	41,977	60.3
United States Dependency	87	5.0	9	4.9	1335	5.0	3066	4.4
Outside United States	226	13.1	25	13.5	5799	21.7	13,566	19.5
Unknown	147	8.5	16	8.6	4111	15.4	11,031	15.8
Borough								
Bronx	683	39.5	78	42.2	9442	35.4	16,330	23.4
Brooklyn	443	25.6	64	34.6	7921	29.7	16,032	23.0
Manhattan	320	18.5	21	11.4	3745	14.0	19,943	28.6
Outside NYC	29	1.7	1	0.5	1273	4.8	5379	7.7
Queens	208	12.0	14	7.6	3495	13.1	10,233	14.7
Staten Island	45	2.6	7	3.8	724	2.7	1381	2.0
Unknown	2	0.1	0	0.0	106	0.4	342	0.5

[a]All cisgender PWH were included, regardless of Medicaid usage.
[b]In care was determined through the presence of at least one CD4 or viral load test result in the HIV registry in the given time period. Sociodemographic data were based on 2017 data, except where individuals died before 2017. In those cases, age and borough of residence at death were used.
[c]For demographic groups where the number who obtained gender-affirming surgery is less than five, we have suppressed these numbers out of concern for identifiability.
FPL, Federal Poverty Level; NYC, New York City.

departments revise their EtE plans to extend beyond 2020.[5,16] An improvement would be to set VS goals specific to the TPWH population.

The current 2020 NY EtE goal for VS among PWH in medical care is 95%.[17] Our findings suggest that all populations in this analysis are in need of greater support to achieve the goal, especially lower income TPWH.

Effective interventions could include combining gender affirmation with health care empowerment[13]; providing peer navigation, education, incentives, flexible and affirming spaces, and hours; and combining medical care with linkage to other services that are associated with increased VS among TPWH.[18,19] The Ryan White HIV/AIDS Program (RWHAP)

Table 2. HIV Viral Suppression of People with HIV Who Are in HIV Care in 2013–2017 in New York City, Comparing Transgender Persons Who Accessed Medicaid to Cisgender Women and Cisgender Men

	Transgender persons in Medicaid							
	All		Those who had gender-affirming surgery		Cisgender women[a]		Cisgender men[a]	
People with HIV characteristics	*N*	%	*N*	%	*N*	%	*N*	%
In HIV care[b] (row %)								
Overall in 2013–2017 ($n=98,951$)	1730	1.7	185	0.2	26,706	27.0	69,640	70.4
By year								
2013 ($n=77,298$)	1208	1.6	147	0.2	22,050	28.5	52,417	67.8
2014 ($n=77,848$)	1289	1.7	154	0.2	21,962	28.2	52,943	68.0
2015 ($n=79,404$)	1400	1.8	174	0.2	22,129	27.9	53,780	67.7
2016 ($n=80,417$)	1490	1.9	180	0.2	22,185	27.6	54,869	68.2
2017 ($n=80,897$)	1531	1.9	181	0.2	22,181	27.4	55,207	68.2
Virally suppressed[c] out of those in care (col %)	($N=1730$)		($N=185$)		($N=26,706$)		($N=69,640$)	
Overall in 2013–2017	1314	76.0	160	86.5	21,481	80.4	57,997	83.3
By year								
2013	806	66.7	112	76.2	16,667	75.6	41,944	80.0
2014	895	69.4	121	78.6	17,232	78.5	43,659	82.5
2015	1029	73.5	146	83.9	17,893	80.9	45,393	84.4
2016	1117	75.0	160	88.9	18,314	82.6	46,848	85.4
2017	1154	75.4	154	85.1	18,241	82.2	47,207	85.5

[a]All cisgender PWH were included, regardless of Medicaid usage.
[b]In care was determined through the presence of at least one CD4 or viral load test result in the HIV registry in the given time period.
[c]Viral suppression was determined by looking at the last viral load test result for the given time period and whether it was <200 copies/mL.

provides medical care and supportive services and is widely lauded for its successes regarding VS.[20] VS was 80.9% in 2017 among TPWH in the RWHAP nationally.[21] Therefore, the NY RWHAP could be a resource to TPWH accessing Medicaid.

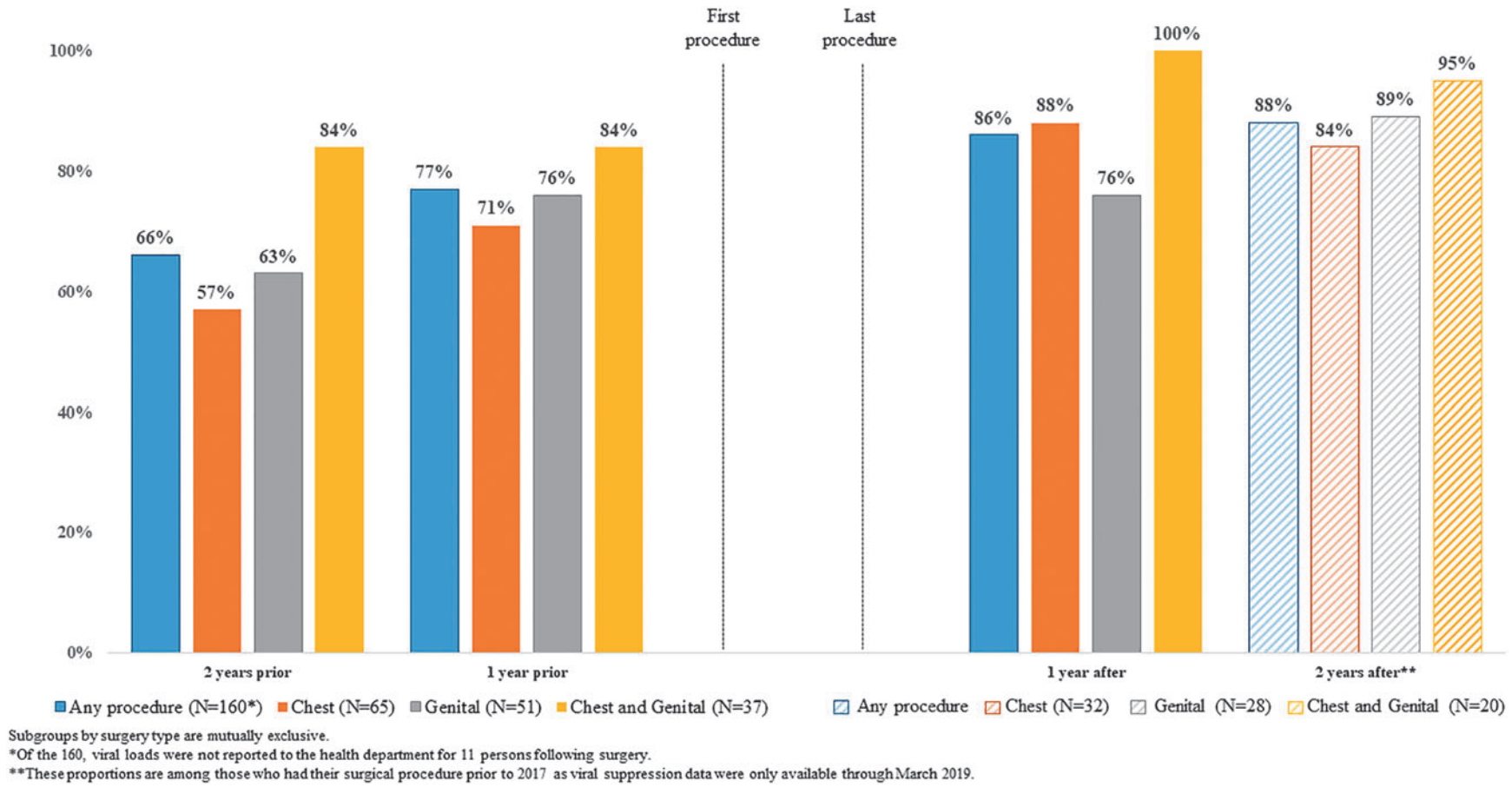
In 2019, The HIV Health & Human Services Planning Council of New York, which determines the spending priorities for NY RWHAP, approved a new and first-of-its-kind psychosocial support service directive specifically for TPWH.[22] It is important that this new program is evaluated for its impact on VS, as well as the mechanisms of any impact, since it may serve as a model for other RWHAPs. In addition, NY Medicaid has HIV Special Needs Plans that provide case management and coordinated care to transgender persons regardless of HIV status, which has the added benefit of preventing acquisition of HIV among transgender persons not diagnosed with HIV and tailored navigation of the HIV service delivery landscape for TPWH.[23]

The subpopulation of TPWH who accessed gender-affirming surgical procedures through Medicaid achieved a VS proportion in 2017 (85.1%) comparable to that of cisgender PWH. VS went on average from 66.3% 2 years before to 86.3% 2 years postsurgery. Access to gender-affirming surgery may have the multiple benefits of improving individuals' long-term physical and mental health and eliminating sexual transmission of HIV to others through VS.[24]

Although a requirement of VS before surgery may have served as a motivator for achieving VS, the improvement in VS persisted postsurgery and may be related to a number of factors, including but not limited to advances over time in HIV medications and care, meeting unmet needs for gender affirmation, greater engagement in medical care that may be associated with obtaining surgery, and baseline characteristics of this group before surgery such as greater psychosocial wellbeing.

VS increased for all surgery type subgroups, but there was heterogeneity by type. Our understanding of these differences is limited by the smaller numbers in each subgroup, the study design, and the descriptive nature of this analysis, warranting both qualitative research in the future to explore how surgery impacts VS and more robust longitudinal study designs to understand temporal trends.

Nonetheless, we feel that there is value in a first exploration of VS before and after gender-affirming surgery. NY's Medicaid program is the largest in the United States; it covers most PWH in NYC, and coverage of gender-affirming surgeries was an important policy change that occurred fairly recently (2015) while many insurers across the United States still deny this coverage.[25,26] TPWH have expressed that gender affirming and nondiscriminatory health care is one of their top concerns,[10] although such surgery is not desired by every TPWH.



Subgroups by surgery type are mutually exclusive.
*Of the 160, viral loads were not reported to the health department for 11 persons following surgery.
**These proportions are among those who had their surgical procedure prior to 2017 as viral suppression data were only available through March 2019.

FIG. 1. HIV viral suppression pre- and post-gender-affirming surgery among transgender persons who accessed Medicaid and achieved viral suppression at last laboratory in 2013–2017 in New York City.

Our findings are particularly notable because this subpopulation was composed of communities who often experience many barriers to achieving VS, including black people, younger people, those living in high-poverty areas, and those living in the Bronx.

It may be that the process of pursuing surgery drives changes in VS as we did not find that VS was uniformly high in the years before surgery; it increased leading up to surgery. Surgery may serve as both a positive influence on health care engagement and self-care behaviors and an opportunity for providers to manage patients' HIV outcomes. If TPWH interact with health systems more often to obtain surgery along with meeting presurgery medical milestones (e.g., mental health assessments), these may serve to improve management of comorbidities (e.g., mental health and substance use disorders) whose control in turn improves VS.

A study of TPWH accessing a Medicaid plan in NYC found that TPWH achieved similar VS as cisgender PWH, that the usage of gender-affirming surgery was high (22% accessed surgery), but that TPWH also presented with high levels of comorbidities.[27] It is worth noting that because a lack of VS might be a reason to deny surgery to TPWH, greater consideration needs to be given to how to make gender-affirming surgery accessible to TPWH who face difficulty achieving VS, but who may in fact desire these surgeries.

There are a number of limitations to this analysis. It relies on transgender persons identified in Medicaid data from an earlier analysis using a combination of billing codes, and thus we do not know if these individuals self-identified as transgender; it may have left out transgender persons who did not have transgender-related coding applied to their claims.[3]

We could not account for those who obtained gender-affirming surgery outside of Medicaid nor for whether TPWH accessed surgery before 2013, and we did not include information on the association between hormone therapy with VS. We were not able to assess whether cisgender PWH had accessed Medicaid, although in NY most do.[5] Had we assessed VS solely among cisgender PWH enrolled in Medicaid, we may have found their VS to be similar to that of TPWH overall enrolled in Medicaid, given that poverty is a barrier to VS.

As for VS pre- and postsurgery, we used first and last surgical procedure that TPWH received as proxy measures to determine VS before and after surgery, introducing some amount of imprecision regarding time since surgery. A broad list of surgical procedures was included, improving our sensitivity to pick up a greater number of TPWH who obtained surgery, but it may have also resulted in comparisons of VS between those who obtained minor surgical procedures to those who had extensive surgeries.

We found a small number of individuals who had had a facial feminization procedure. Future studies should investigate VS among those who have had facial feminization procedures. Given that the face may be more relevant for signaling one's gender, it could be that there will be a stronger association between obtaining facial feminization and VS.

At the time of this analysis, we did not have viral load data through the end of 2019 for those who obtained surgery in 2017. Therefore, VS may be over- or underestimated for our proportions suppressed 2 years postsurgery. We did not assess some potentially important moderators and mediators of the surgery-VS association, such as mental health status or treatment. Nonetheless, this description of associations between gender-affirming surgery and VS is a first step in exploring a broader set of health outcomes for TPWH than we have previously had the capacity for.

Conclusions

Most (79%) TPWH in NYC are accessing Medicaid, making it a critical program for the health and well-being of TPWH, a population requiring intensive, holistic support to achieve VS. Medicaid is likely also an important safety net for TPWH in jurisdictions across the country. Although great strides were made in VS among NYC TPWH enrolled in Medicaid in 2013–2017, the proportion suppressed was consistently lower than that of cisgender populations, except in the case of the subset of TPWH who had obtained gender-affirming surgery through Medicaid. This latter subpopulation also sustained high VS postsurgery, an important achievement in light of the difficulty of sustaining VS for TPWH overall in NYC.

Although assessing the effect of gender-affirming surgery on VS is a relatively new topic, our findings suggest that these surgeries may improve VS, but more robust study designs and analyses of potential mechanisms of this relationship (e.g., mental health and retention in care) should be explored in future research of TPWH.

Authors' Contributions

C.R.-H., G.Z,. A.R., Z.G., and L.T. were involved in the conceptualization, review of relevant literature, study

design, data interpretation, and writing of the article. C.R.-H. and G.Z. conducted the data analysis. All authors have read and approved the final article.

Author Disclosure Statement

No competing financial interests exist.

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Abbreviations Used

CPT = Current Procedural Terminology
EtE = Ending the HIV Epidemic
ICD = International Classification of Diseases
NCD = National Coverage Determination
NYC = New York City
RWHAP = Ryan White HIV/AIDS Program
TPWH = transgender persons with HIV
VS = viral suppression